

Systematic Review on Supportive Counselling for Caregivers of Dementia Patients in Sub-Saharan Africa

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Abstract

As people get older, there is an increased tendency to develop health disorders. Dementia has been identified as very prevalent among older people especially those older than 65 years of age. The purpose of the systematic review was to identify and highlight current information, synthesize and appraise evidence as well as bridge any existing knowledge gap in supportive counselling for caregivers of dementia patients in Sub-Saharan Africa. This study aims to investigate support for caregivers, their efficacy, challenges as well as opportunities linked to their implementation. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) using key search terms in conjunction with Boolean operators (OR/AND) was utilized for this review. A total of nine (9) studies which met the inclusion criteria were included in the final synthesis. The findings of this study showed that caregiving for dementia patients in Sub-Saharan Africa is mostly informal and caregivers lacked adequate knowledge on dementia. Also, caregivers suffer significant physical, emotional and psychological distress as a result of caring for the ill individuals. There is a gross lack of counselling services for dementia caregivers in SSA and this further intensifies the act of neglect of dementia patients in the region.

Keywords— Dementia, Supportive Counselling, Caregivers, Caregiver Burden, Health Psychology

I. INTRODUCTION

Aging is a natural process in humans characterized by a gradual functional decline in health, mobility, psychosocial ability, cognitive functions and general well-being usually originating at the molecular, cellular, tissue, and organismal levels (Booth & Brunet, 2016). Over the past decades there has been a steady rise in the population of older people especially those that are 60 years and older. Africa, especially Sub-Saharan Africa has had its fair share of the burden of older persons (Wakawa et al., 2024). Available statistics indicate that between 1980 and 2020, the population of older adults soared from approximately 24 million to 74 million and this has been predicted to triple between 2020 and 2050 (Mbam et al., 2022). With aging comes frailty, higher risk of

disease and greater possibilities of dying. Older people have been shown to be at greater risk of developing several diseases including mental health disorders (dementia, Alzheimer's disease, depression, etc), diabetes, osteoporosis, cancer, cardiovascular diseases etc (Kennedy et al., 2014). According to Qaseem et al. (2008), dementia is a severe neurodegenerative disorder which affects older adults and consist of a collection of acquired symptoms associated with impaired cognitive functions in memory, language, and goal-directed behaviours. Dementia reduces a person's ability to carry out normal activities of the day as well as lowers quality of life (Salcher-Konrad et al., 2019). An estimated 90% of dementia patients are reportedly affected by behavioural and psychological symptoms as the illness

progresses (Kolberg et al., 2021). Dementia is more prevalent among older adults above 65 years of age and often associated with comorbidities. There is also some level of difficulty in assessment and treatment because patients may not provide adequate medical history for doctors and caregivers (Livingston et al., 2017; Draper et al., 2018). A 2015 study estimated that about 2.13 million people were living with dementia in sub-Saharan Africa (SSA) and this figure was projected to increase to at least 7.62 million in 2050 (Guerchet et al., 2017). According to Prince et al. (2016), a greater population of older people living with dementia globally are from low-and-middle income countries (LMICs)-of which Sub-Saharan Africa constitutes a large proportion-and it has been estimated that this figure will rise to at least 71% in 2030. Despite these staggering statistics, literature is packed with studies from high-income countries (HICs) and interventionist programs from such studies may not apply to Sub-Saharan Africa numbers due to difference in care needs by patients, healthcare structure and environments and socio-cultural dynamics (Mushi et al., 2014). Based on the severity, dementia may show impairment in different areas of cognitive functioning e.g. executive dysfunction, affectation of memory, behavioural changes, impairments in instrumental and basic activities of the day (Budson & Solomon, 2021; Calsolaro et al., 2021; Cipriani et al., 2020). It has also been observed that dementia is often associated with other medical and psychiatric comorbidities (Bunn, et al. 2017). Dementia is so complex that the impacts of the illness does not only affect the patient but also significantly affects the caregiver (Connors et al., 2020). Dementia is more problematic in Sub-Saharan Africa due to poverty and poor amenities (Akinyemi et al., 2022).

Several approaches exist for the management of dementia. Some of them include pharmacological intervention, community-based and family caregiving, traditional and customary care practices as well as rehabilitation programs (Alemayehu et al., 2025). According to Paddick et al. (2017), treatment outcomes for dementia patients are often poor and is associated with substantial disability and highly burdensome on the caregiver. The most prevalent methods of intervention for dementia patients is community-based and family caregiving which accounts for up to 90% of all support received by dementia patients (Alemayehu et al., 2025). However, these carers have no formal training hence they are faced with severe emotional and economic burden. Sub-Saharan Africa is also faced with the

problem of poor manpower with respect to psychiatrists, neurologists, geriatricians, or trained mental health workers compared to HICs (Dotchin et al., 2013). While the strategy adopted by World Health Organization (WHO, 2015) in response to mental health disorders in LMICs is to increase healthcare provision through training of primary health workers to deliver interventions, the impact of caring for dementia patients by caregivers has not been given adequate attention. Several challenges have been identified including late presentation and diagnosis, limited access to specialist care, poor healthcare infrastructure and resources (especially diagnostic tools and equipment), and a lack of culturally appropriate interventions represent unique challenges in the management of dementia in these settings (Bernstein-Sideman et al., 2022; Kalaria et al., 2024). In most low-income countries especially those in Sub-Saharan Africa, dementia is often viewed as a normal component of ageing and is not given attention as requiring medical treatment (Beyene & Berha, 2023).

At the core of management and treatment of dementia sits caregivers. In HICs, there are trained professional caregivers, while dementia patients from LMICs are faced with informal caregivers who are not trained nor earn a wage for providing care (Kehoua et al., 2019). Due to poor understanding and cultural beliefs, in most SSA countries dementia patients are viewed as witches or wizards and are most often abandoned for care by traditionalists and syncretic churches (Kehoua et al., 2019). Dementia patients are also often excluded from family, community and societal settings and allowed to suffer without care (Mushi et al., 2014). Caregiving in this context is mainly an informal role, usually assigned to family members without any description of the scope and extent of care expected and in most cases the carers see the patient as a burden (Kehoua et al., 2019). Providing care for dementia patient is no doubt a herculean task because the caregiver has to manage the changing demands and expectations of the patient. It has been reported that to a large extent caregivers often sacrifice their own needs and well-being while caring to the patient. According to Tremont (2011) this distress experienced by a caregiver as a result of caring for a dementia patient is called caregiver burden. Caregiver burden is multifaceted including both objective aspects of providing care (e.g., time and physical aspects of providing caregiver) and subjective experience of caregiving (e.g., perceptions and emotional reactions to caregiving). Ultimately, if caregiver burden is not eased,

it will lead to mental health consequences e.g. depression.

Caring for dementia patients has both physical and mental health consequences. Reports have shown that it is more demanding to care for a dementia patient than it is to care for a physically-impaired older adult (del-Pino-Casado et al., 2018). Dementia caregivers have been reported to show elevated levels of depression, anxiety, mood disorders which often worsened with longer hours of care provided to the patient (Davis & Tremont, 2007). It has been previously reported that unsatisfying prior relationships and poor family functioning are associated with greater reactivity to memory and behaviour problems and less burden compared to individuals with satisfying pre-dementia relationships (Lea Steadman et al., 2007; Tremont et al., 2006). It has also been shown that caregivers with greater depression and burden (in cases where the patient dies) may be at higher risk of prolonged grief (Tremont, 2011). Caregiving for dementia patients has also been shown to have physical health impacts on the carer (Vitaliano et al., 2003). It has been suggested that the chronic stress as a result of caring for a dementia patient may have negative impacts immunological and hormonal function thus increasing susceptibility of the care to illnesses (Tremont, 2011). Vitaliano, et al. (2003) also reported that carers for dementia patients may neglect their own health such as sleep deprivation and poor nutrition which both predispose them to illnesses. Factors which predispose carers to poor health include extended durations of caregiving, low socioeconomic status and education, poor informal support, behaviour problems and cognitive impairment in the dementia patient, older age, living with patient, not being a spouse, and high levels of depression/burden (Pinquart, & Sörensen, 2007). Female caregivers have been reported to display poorer health outcomes than their male counterparts (Baboolal, et al. 2018). In some cases the health of caregivers has progressively declined even up to development of cognitive impairment and death with a 63 % increased death risk compared to non-caregivers within a 4 years duration (Gaugler et al., 2018). Also, spousal caregivers showed increased rate of mortality following hospitalization of their spouse than non-spousal caregivers (Reinhard et al., 2008). There has also been a reported six-fold elevated risk of dementia in spousal

dementia caregivers compared to non-caregivers (Wang et al., 2024).

Despite the immense impact of dementia of caregivers, within the SSA there has been limited interventions to lessen the impact of dementia on caregivers. The purpose of the systematic review is to highlight current information, synthesise and appraise evidence as well as bridge any existing knowledge gaps in supportive counselling for caregivers of dementia patients in SSA. This study will also investigate counselling approaches, their efficacy, challenges as well as opportunities linked to their implementation. Findings from this study is expected to drive future research, influence policy and improve the status of caregiver-focused psychosocial interventions in Sub-Saharan Africa.

II. METHODS

2.1 Search strategy

Using Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), articles were searched on Google Scholar and PubMed. Manual searches were done in Google Scholar. Search term used include The following search terms were used in this study: "Dementia", "dementia caregiver", "informal caregiver", "family caregiver", "Sub-Sahara Africa", "Ghana", "South Africa", "Uganda", "Kenya", "Nigeria", "Ethiopia", "Tanzania", "counselling intervention", "psychological support", "mental health counselling", "supportive counselling", "emotional support", "psychosocial support", "talk therapy", "psychological well-being", "depression", "emotional distress", "caregiver burden", "caregiver stress", "mental health", "quality of life". The Boolean operators (OR/AND) were used with these key search terms to boost the relevance of the search results.

2.2 Inclusion and exclusion criteria

The results obtained from the searches were examined focusing on titles and abstracts to ensure they fit into the criteria for inclusion in this review. The search was limited to the period from January 1st 2015 up to 4th August, 2025. The inclusion and exclusion criteria are outlined in table 1. All authors independently assessed and screened the studies which met the inclusion criteria prior to final synthesis.

Table 1: Inclusion and exclusion criteria

Criterion	Inclusion	Exclusion
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Language	English	Non-English
Timeline	20150101-20250804	Publications outside the chosen dates
Article type	Articles on caregiving and dementia	Articles not focused on inclusion criteria
Availability	Full articles available for download.	Articles unavailable for download.
Study type	Primary studies	Secondary studies

2.3 Ethical consideration

The included studies were properly referenced and cited to avoid issues of plagiarism. To reduce bias, the selection of studies to include, the establishment of inclusion and exclusion criteria, the extraction of data, and the explanation were all carried out in an impartial and open manner.

III. RESULTS AND DISCUSSION

The systematic search for literature yielded a total of 9 articles (appendix II) which met the inclusion criteria and were subsequently subjected to data extraction and interpretation (table 2).

A study by Gurayah (2015) aimed to investigate the concept of caregiving in a rural community in South Africa. The study involved five (5) caregivers who were administered interview questions on caregiving for dementia patients. The findings of the study showed that caregivers generally asserted that caregiving helped build their character however, they also suffered significant effects such as feelings of social isolation, restricted daily activities, lowered chances of employment, increased financial burden as well as psychological challenges e.g. anxiety and depression. However, caregivers did not receive any form of counselling support to manage their emotional and psychological challenges.

Abaasa et al. (2019) carried out a qualitative investigation on psychosocial supports utilized by caregivers of patients with dementia in south western Uganda. Participants from in this study were recruited from three major psychiatric hospitals- Mbarara Regional Referral Hospital (MRRH), Kabale Regional Referral Hospitals (KRRH), and Kampala International Teaching Hospital (KIUTH)- all located in Southwestern Uganda. Data collection was through a well-structured interview. The study involved thirty-four caregivers across the various healthcare institutions. interviews were conducted across the three hospitals in southwestern Uganda. Majority of the caregivers were family members aged

between 44 and 53 years, most of them had formal education and had been caring for the dementia patient for over five years. Only 2.9% of caregivers in this study were not related by blood to the dementia patient they were caring for. Although participants reported to have received counselling/educational support from healthcare professionals, they reported not to have received any form of emotional support. The participants also highlighted that places to get counselling from were non-existent or they were not aware. Participants also appealed for the establishment of counselling services to enable them combat the challenges inherent in caring for dementia patients. The only form of emotional support reported by the participants was from religious leaders, family members and community members. However, this form of support was not in any way counselling support rather it was an encouragement to continue doing the work of caring for the patient.

In another study by Ainamani et al. (2020), caregiving burden and mental health problems among family caregivers of people with dementia in rural Uganda was investigated. In this cross-sectional study involving a total of 232 family caregivers of people with dementia, the variables of interest were measured using variables of interest were caregiving burden (Zarit Burden Index) and symptoms of depression and anxiety (Depression Anxiety Stress Scales). There was a slightly higher proportion of male caregivers compared to female caregivers in the study. The findings showed that over 70% of participants experienced significant caregiving burden associated with caring for dementia patient, however, there was no report of any of them receiving counselling support. Caregiving burden was associated with elevated risk of developing depression and anxiety. The study thus concluded that there should be interventions aimed at reducing caregiving burden on the caregivers to prevent future mental health problems. The findings of these study agree with other researchers to assert that in SSA there existed no formal counselling support for caregivers who are caring for dementia patients, rather caregivers only get little emotional

support from family, friends and religious communities (Agyeman et al., 2019; Lambert et al., 2017).

Nwakasi et al. (2021) investigated caregivers' attitudes about Dementia and caregiving in Nigeria. This qualitative descriptive study involved twelve (12) female Nigerian dementia caregivers. Data was collected through semi-structured interviews and the findings showed that knowledge deficit and stigma were associated with caregivers because of the traditional beliefs that dementia was a sign of witchcraft or something evil. The caregivers had poor attitude to caregiving for dementia patients and did not seek or receive any form of counselling to handle the psychological effects of caregiving.

Mahomed & Pretorius (2022) aimed to understand the lived experiences of family caregivers of individuals with dementia in Soweto, a South African Township. The study adopted purposeful sampling technique and data was collected using well-structured interview questions. In all, there were 30 participants in this study and thematic areas included Understanding Dementia, Struggles and Sacrifice, Mental Health and Protective Factors. Although the duration of the experiment was not clearly stated by the authors, the study made some very important findings such as the fact that family caregivers and their communities understood dementia, the sacrifices and struggle they faced, the impact of caregiving on their mental health and likely factors to protect them from its harmful impacts. The findings of this study corroborates the findings of previously reported studies that caregiving for dementia patients was mainly done by family members, community members or friends. Also, the superstitious belief that dementia is associated with witchcraft was not evident here as the participants had some fair knowledge about the progression of the disease among caregivers. Furthermore, participants attested that caregiving had negative effects on their mental health and manifested as anxiety, stress and grief reactions. The participants also unanimously asserted that they did not receive any form of counselling or emotional support.

Owokuhaiza et al. (2023) in a study sought to explore the burden of caregiving for dementia patients as well as coping strategies in rural communities in Uganda. The study focused on the burden experienced by informal caregivers in the course of caring for dementia patients. It was a qualitative study involving 27 caregivers who provided data for the researcher via an interview.

Caregiver burdens identified were categorized as physical, financial, social and psychological. Participants expressed anger, fear, social exclusion and judgement from people. The findings of this study indicate that participants received informal emotional and psychological support and counselling religious leaders, friends and family members. They had no formal counselling support mainly because such services were non-existent in their environment.

A study was conducted in Tanzania by Walker et al. (2023) to assess patient and caregiver experiences of living with dementia. The study adopted a qualitative semi-structured interview design and involved twelve (12) caregivers. The findings of the study showed that despite the immense psychological and emotional impact of caregiving on the caregivers there were no counselling services for caregivers. Just like other reports, caregivers were mainly informal, lack education and were family members, friends or relatives.

Duodu et al. (2024) conducted a study in Ghana focused on coping mechanisms adopted by family caregivers' of dementia patients. The study was based on a descriptive phenomenological design, in which data was collected through interviews. A total of thirty (30) unpaid family caregivers of dementia patients participated in the study. The caregivers were observed to be under severe strain associated with caring for the dementia patient and they adopted coping mechanisms including empathy and perspective-taking, family support and cohesion, coaxing and pampering of persons living with dementia, humour and positive communication and spiritual support. These mechanisms were adopted by the caregivers to cope with the patients however there was no consideration of the psychological effects of caregiving on the caregivers and the need for emotional and psychological support. The study highlighted the need for psychosocial support services to help ameliorate the stress faced by caregivers and to prevent burnout; the positive outcome of such initiative is that it will help improve the care being given to the dementia patient. The study reported the lack of counselling and support services for caregivers in Ghana.

Gumikiriza-Onoria et al. (2024) investigated the feasibility and acceptability of the World Health Organization's iSUPPORT program for dementia caregivers in Uganda. The study lasted four weeks (and involved 65 caregivers) and mental health conditions of participants were assessed using the Kessler Psychological Distress Scale

(K-10), the Centre for Epidemiological Studies Depression Scale (CES-D), and the Measure of Quality of Life for Dementia Caregivers (C-DEMQL). All these scales were translated to a local language (Luganda) before administration. The participants were divided into intervention group and control group. The findings showed that the intervention group (those who were exposed to the WHO's iSUPPORT program for dementia experienced substantial improvements in psychological distress, depression and quality of life while the control group did not experience such. There was a very high rate of positive feedback from participants and this goes to show the effective nature of the program in boosting the well-being and mental health of caregivers from SSA.

In most SSA countries, just as is also obtainable in developed countries of the world, caregiving for dementia patients is informal and administered by family, friends or spouses (Krutter et al. 2020). The goals of caring for dementia patients in clinical settings which include preservation of functional status, the ability to work, maintaining ability to live at home, maintaining mobility, controlling behavioural and psychological complications, and reducing caregiver burden, is often difficult to achieve in informal settings (Jennings et al., 2017). In most cases, these carers do not have adequate knowledge on the ailment and they often end up with various forms of psychological impacts. Despite the increasing number of dementia cases in the SSA region, counselling and support services continue to be grossly inadequate or non-existent, as evidenced in this review. This review outcomes coincides with the reports of other researchers on the extent and impact of dementia on both patients and carers (Tremont, 2011; Wang et al., 2014; Yakubu & Schutte, 2018; Hailu et al., 2025).

IV. CONCLUSION

Dementia is an illness which affects older people in the society. In SSA countries, several misconceptions have been associated with dementia and this has to a large extent affected the care and attention given to the ailment. While families and friends are left to care for their sick aged individuals, the impact of caring on the carers has not been given proper attention. The findings of this study indicates that while few sources have identified counselling programs for caregivers, a vast majority of studies have not mentioned the existence of such services nor carers accessing such services. The burden of dementia will continue to grow as the

population of older people continues to increase and this will eventually create a larger burden on the society where people who have cared for dementia patients will be needing care themselves. The poor healthcare facilities, poor fundings, superstitious beliefs and myths as well as government insensitivity to the plight of dementia patients and carers will continually place a strain on society. The World Health Organization advises that multi-sectoral support networks work to avoid caregiver burnout and promote mental wellness.

DISCLOSURE OF INTEREST

The authors report no conflict of interest.

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APPENDICES

Summary table of findings

Title	Author(s) / year	Country	Method	Key findings
1. Caregiving for people with dementia in a rural context in South Africa	Gurayah (2015)	South Africa	Interview	No support to caregivers to care for their emotional and psychological implications of caregiving for dementia patients.

2. Psychosocial supports utilized by caregivers of patients with dementia in South western Uganda: A qualitative investigation	Abaasa, et al. 2019	Uganda	Interview	There was little or no psychosocial support to caregivers of dementia patients
3. Caregiving burden and mental health problems among family caregivers of people with dementia in rural Uganda	Ainamani, et al. 2020	Uganda	Cross-sectional	Caregivers felt a very high burden caring for their loved ones but received no form of counselling support.
4. We are doing these things so that people will not laugh at us”: Caregivers’ attitudes about dementia and caregiving in Nigeria	Nwakasi, et al. (2021)	Nigeria	Semi-structured interviews	Caregivers do not have access to counselling services.
5. Understanding the lived experiences of family caregivers of individuals with dementia in Soweto, a South African Township	Mahomed, & Pretorius, (2022)	South Africa	Interview	Participants attested that caregiving had negative effects on their mental health and manifested as anxiety, stress and grief reactions. The participants also unanimously asserted that they did not receive any form of counselling or emotional support.
6. Informal caregivers of people with behavioral and psychological symptoms of dementia in rural south-western Uganda	Owokuhaiza, et al. (2023)	Uganda	Cross-sectional	The findings of this study indicate that participants received informal emotional and psychological support and counselling religious leaders, friends and family members. They had no formal counselling support mainly because such services were non-existent in their environment.
7. Patient and caregiver experiences of living with dementia in Tanzania	Walker, et al. (2023)	Tanzania	Qualitative semi-structured interviews	There was a lack of counselling and support service for caregivers in Tanzania.
8. Exploration of family caregivers’ experiences on coping in dementia care in Ghana: a phenomenological study	Duodu, et al. (2024)	Ghana	descriptive phenomenological design	There is a gross lack of counselling and support services for caregivers in Ghana

9. Feasibility and acceptability of the World Health Organization's iSUPPORT program for dementia caregivers in Uganda.	Gumikiriza-Onoria, et al. (2024)	Uganda	Randomized clinical trial (RCT)	UGA-iSUPPORT effectively boosted the mental health and well-being of dementia caregivers in LMICs especially with respect to psychological distress, quality of life and depression.
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Appendix II: CASP scores for included articles

Appendix II: CASP scores for included articles

1 st author (year of study)	CASP criterion ^a										Total Score ^b
	1	2	3	4	5	6	7	8	9	10	
1. Gurayah (2015)	2	2	2	1	1	1	2	2	2	2	17
2. Abaasa, et al. (2019)	2	2	2	2	2	0	2	1	2	2	17
3. Ainamani, et al. (2020)	2	2	2	2	2	0	2	2	2	2	18
4. Nwakasi, et al. (2021)	2	2	2	2	2	0	1	2	2	2	17
5. Mahomed, & Pretorius, (2022)	2	2	2	2	2	0	2	2	2	2	18
6. Owokuhaiza, et al. (2023)	2	2	2	1	2	1	2	2	2	2	18
7. Walker, et al. (2023)	2	2	2	1	2	2	2	2	2	2	19
8. Duodu, et al. (2024)	2	2	2	1	2	2	2	0	2	2	17
9. Gumikiriza-Onoria, et al. (2024)	2	2	2	2	2	0	2	2	2	2	18

^a**CASP criterion:** 1. Did the research state the aim clearly? 2. Appropriateness of methodology? 3. Appropriateness of design of research to address research aims? 4. How appropriate was the method recruitment of participants aimed at achieving the purpose of the research? 5. Was data collection done appropriately to address the research objectives? 6. Was researcher-participant relationship put into proper consideration? 7. Were ethical issues considered? 8. How sufficient and rigorous was the data analysis? 9. Were the findings clearly stated? 10. Is the research valuable?

^b**CASP critical score:** a score of 2 is allotted if a particular criterion is totally met; 1 for partial and 0 if the criterion is not applicable to the study, it is not mentioned or is not met. Usually, a maximum score is 20 is possible however, values equal to or less than 15 are considered low quality while values above 16-19 are graded as moderate quality while 20 is high quality